Last Month

Ichthyosis Awareness Week 24th - 30th September Thank you to all of you who supported the week by holding fundraisers or simply ‘spreading the word’. Many of you visited hospital departments, GP surgeries and schools talking to people, leaving literature raising awareness and educating people about ichthyosis. The ISG contacted about 450 dermatology departments across the UK and Ireland, encouraging them to display our literature and pass on details about the ISG to new and existing patients.

Run for it, 11th September, Thrupton [www.justgiving.com/Amanda-Sullivan] Amanda Sullivan, ISG member and mum to Elliot, took part in this 2.4 mile run to help raise awareness of ichthyosis. Amanda’s efforts raised £335 for the ISG and inspired her to run in future events. Well done Amanda! You can view photos of the event here: [www.excipio.me/gallery/HIOWAA-Run-for-it/G0000Y18U7ag6aC4]

Adidas Women’s 5K Challenge, 11th September, Hyde Park [www.justgiving.com/teamskindeep] Laura Levy, Regional Contact for London, teamed up with some friends and family to run for the ISG. Fun was had by all and ichthyosis certainly had a presence at the event, with the team wearing the ISG T-shirts. In addition, Laura also organised a ‘Club Night’ to kick start ‘Ichthyosis Awareness Week’ in her region.

Berlin Marathon 25th September 2011 Sean Hagger, friend and colleague of Clive Bowen, founder member of the ISG who is dad to Dana & Lara who both have harlequin ichthyosis, took part in the Berlin Marathon last month finishing in 4hrs 27 minutes and 37 seconds - raising over £500 for the ISG. Well done Sean.

Coast to Coast Bike Ride Staff at Coventry ‘Royal Mail’ teamed up with ISG member Danny Oldacres, who has a 3 year old son with Netherton Syndrome, to make the 140 mile trip from Whitehaven on the west coast of the UK to Sunderland on the east. The two day journey helped raise awareness and money for ichthyosis. [www.justgiving.com/John-Hamm2]

Specialist Registrar Training, 30th September Mandy Aldwin, ISG Trustee, attended this event by invitation from Professor Celia Moss, Birmingham Children’s Hospital, who was delivering a presentation on the different ichthyoses. Mandy attended the training day for doctors, giving a patient’s perspective of ichthyosis, at the British Association of Dermatologists (BAD) House, last month ending ‘Ichthyosis Awareness Week’ very positively.

Feedback from medics suggests teaching and presentations from patients enhances their practice.

ISG Members Events

*Nottingham Ultramarathon, 9th October 2011*
Michael Shelton is running for the ISG
To support this event please visit: [www.justgiving.com/Michael-Shelton]

Forthcoming Events

Specialised Healthcare Alliance Meeting
Wednesday 12th October, London.
[www.shca.info/]

Dermatology Council for England
Thursday 13th October, London

Genetic Alliance AGM 1st November, London
[www.geneticalliance.org.uk/]

British Society of Paediatric Dermatology (BSPD)
AGM 11th & 12th November, Nottingham
[www.bspd.org/]

British Association of Dermatologists (BAD) Patient
Support Group (PSG) Committee Meeting, Thursday
17th November, London
[www.bad.org.uk/]

Please note: an ISG representative aims to attend these meetings, as they are not intended for the general public. If you have an interest in any of the above please contact the ISG at: isg@ichthyosis.org.uk
Auction Monkey  
ISG member Katie - Louise Oakley responded to our request to take part in 'Ichthyosis Awareness Week' by creating a cute monkey called Polly to auction through Facebook. This was not only an inspirational way of fundraising but also helps to raise awareness of ichthyosis. To bid for 'Polly' and support Katie's efforts please click on the link below and give Polly a home

To access this link you need to be a Facebook user, and logged in, if you do not have a Facebook account, and would like to bid, please email: isg@ichthyosis.org.uk

New members to the ISG  
During September, the ISG welcomed 19 new members to the group. One of the aims of the ISG is to reach more people and offer support and information to all those affected by ichthyosis and we are contacted regularly by people from all over the world. Last month we received enquiries from sufferers all over the world as well as doctors, family liaison workers and journalists.

Specialised Service for Ichthyosis  
Many of you may be aware the ISG is supporting a proposal to nationally commission a service dedicated in diagnosing, treating and managing people with severe ichthyosis. Feedback from our members strongly suggests there is a definite need for such a service and that treatment locally is not always appropriate or effective. If this service were to be funded by the NHS the aim would be for it to work closely with local services but in addition have dedicated multidisciplinary ichthyosis clinics and outreach nurses to deal with the more severe cases. Last month Mandy Aldwin, ISG Trustee, Liz Dale, ISG Administrator, Professor Edel O’Toole, Dr David Paige and specialist nurse, Jean Robinson met with members of the National Specialised Commissioning Team (NSCT) www.specialisedservices.nhs.uk/ to discuss how this may be achieved and how services for people with ichthyosis can be improved. Further information to follow.

Incorporation of the ISG  
Recently the ISG underwent some changes by becoming an Incorporated organisation. As a result the Ichthyosis Support Group is now a company limited by guarantee and incorporated in England and Wales - the Company No. 7609904 and Charity No. 1142457. These changes were important due to the progression of the group. For more details about how and why the ISG became incorporated, please visit: www.ichthyosis.org.uk/3226/incorporation-of-the-isg/

Text Giving  
If you are fundraising or want to make a donation, it couldn’t be easier - simply text your donation to 70070 and use unique code ICHT14 followed by £10 to make a £10 donation for example.

The ISG Needs Your Help

ISG Volunteers Needed  
Do you have some spare time, a skill or a particular interest that you feel you may be able to assist the ISG with? Do you feel there are areas within the ISG that could be improved upon and are able to contribute? If you have any ideas, or would simply like to get involved, please contact the ISG by tel: 0845 602 9202, email: isg@ichthyosis.org.uk or post: PO Box 1404, Bagshot, GU22 2LS.

Satisfaction in Life for Children With Own Report Measures (SILCWORM)  
Some paediatric doctors at University College London have developed a quality of life measure for children aged 4 to 10 years old with chronic illnesses, such as ichthyosis. For more information, or to take part in the survey, please visit: www.wazdaka.com/silcworm

Survey of ISG Members  
The ISG would like to find out a little more about its members and how they manage their ichthyosis. The aim is to try to work towards improving services for those affected by the condition. If you have not yet completed the survey, and would like to, please visit: www.surveymonkey.com/s/nationalISG

X Linked Study Birmingham - participants wanted!  
The University of Birmingham and Birmingham Children’s Hospital have jointly set up a research study with boys and men aged from 6 to 30 years, with X-linked recessive ichthyosis (XLI). If you fall into this category, and would like to take part, please contact Dr Jan Idkowiak j.idkowiak@bham.ac.uk

X Linked Study Wales - request for participants  
A research team at Cardiff University is carrying out a study looking at adults (aged 18 - 60 years) in the Cardiff area affected by X-linked ichthyosis - compared to their non affected male siblings. If you would like to participate or require further information, please contact the team on tel: 0292 074 2672 or email: RXL1study@cardiff.ac.uk
Top Tips For Ichthyosis

Hospital and doctors appointments - Many people with ichthyosis see varying health professionals for different aspects of the condition. Some of our members have expressed concerns about the treatment and care they receive and often feel they don’t see the right professionals. Below are some tips that may help when attending appointments.

- Don’t be scared to ask questions, make a list before your appointment of things you want to discuss.
- Be open and honest and don’t be afraid to question or challenge people’s opinions, you know yourself and your condition and how it affects you better than anyone.
- Make sure you are comfortable with your doctor or consultant. If there is a breakdown in the relationship, ask to change to another. It is acceptable to do so and you will not be treated any differently.

Members and Fundraising

Justgiving ISG Currently we have 21 live Justgiving pages. To view ours supporters’ pages please visit: www.justgiving.com/isg and see the various ways people are fundraising for the ISG.

Donations & Fundraising Thank you to the following who have all made donations or carried out fundraising events during the last month:

- Mrs A Elliott, grandmother to Joseph who has CIE, who very generously made an exceptional donation.
- Normanby Methodist Wives club for their kind donation.
- Enfield County School for the donation from one of their teachers.
- Dr Mary Judge, who took part in the Manchester 10k run and once again kindly supported the ISG.
- Anne Anstey, who made a donation last month.
- Mr Carter for his donation and merchandise order.

With thanks to all those who have either donated or participated in fundraising events. Without your hard work the ISG would struggle to support those affected by ichthyosis and would not be able to support ongoing medical research. Every penny counts, no matter how small.

If you have an ISG collection box, please do not forget to empty it and send in your cheques.

Useful Links

Easy Fundraising & Easy Search – To help raise money for the ISG register to shop online with over 2,000 well known retailers at www.easyfundraising.org.uk/. Also go to easy search www.easysearch.org.uk/ and select the Ichthyosis Support Group. Both are free to use.

ISG Facebook - Remember to help raise awareness, publicise events and meet new members by registering with, and using, the ISG Facebook en-gb.facebook.com/pages/Ichthyosis-Support-Group/301038155873?v=info.

Ebay For Charity - Donate a % to the ISG from your online sales www.ebay.co.uk/ebayforcharity/.


Payroll Giving - Another easy way to donate to charity direct from your pay www.payrollgiving.co.uk/.

Shop2fundraise - Online shopping where a percentage goes to the ISG. For more information visit: www.shop2fundraise.co.uk/schools/ichthyosis+Support+Group-387742 and to start shopping click the following link www.shop2fundraise.co.uk/directory.php?Ichthyosis+Support+Group.